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**Stakeholders' views of recurrent sore throat, tonsillitis and their management:
a qualitative interview study for the NAtional Trial of Tonsillectomy IN Adults
(NATTINA Part 1)**

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Abstract

Objectives

To determine the impact of recurrent sore throats and tonsillitis in adults and stakeholder views of treatment pathways.

Design

Qualitative semi-structured interview design reporting novel data from a feasibility study for a UK national trial of tonsillectomy in adults.

Setting

Nine study sites linked to Ear, Nose and Throat departments in National Health Service hospitals located across the United Kingdom.

Participants

Fifteen patients, 11 general practitioners and 22 Ear, Nose and Throat staff consented to in-depth interviews which were analysed using a Framework Analysis approach.

Main outcome measures

Views of stakeholder groups

Results

Recurrent sore throats were reported to severely impact patients' family, work and social life. Ear, Nose and Throat staff stated that patients faced increasing barriers to secondary care service access. General practitioners were under pressure to reduce 'limited-clinical value' surgical procedures.

Conclusions

The findings from this study suggest that there is a disconnect between the attitudes of the stakeholders and the reality of recurrent sore throat, tonsillectomy procedures and service provision. More evidence for the role of tonsillectomy is needed from randomised controlled trials to determine whether it should continue to be ranked as a Procedure of Limited Clinical Effectiveness.

Introduction

The role of tonsillectomy in the management of adult recurrent sore throat remains uncertain. A Cochrane review [1] identified only two evaluable adult trials with 156 participants over 5-6 months follow-up and concluded that reasonable levels of evidence were only available for children. Despite demonstrable compliance with Scottish Intercollegiate Guidelines Network (SIGN) [2] and the Royal College of Surgeons of England Commissioning Guidelines [3], UK regional variation in tonsillectomy rates persists [4]. Decision making for recurrent sore throats is mostly undertaken in primary care where there is greatest potential for evolution in the patient pathway. Tonsillectomy is a painful procedure [5] requiring two weeks off work [6, 7]. UK primary care now restricts referrals for treatments they deem to be of limited-clinical value [8] with tonsillectomy ranked top as a ‘relatively ineffective’ procedure [8]. Yet there are twice as many annual hospital admissions related to throat infections than there are for tonsillectomy in England [9]. Sore throats cost the National Health Service (NHS) over £120 million per annum – an estimated £60 million of this for GP consultations and medical therapy [10].

In terms of patient Quality of Life (QOL), evidence from cohort studies and randomised controlled trials report tonsillectomy to be an effective treatment [11-13]

[14, 15] [16]. However, there is a paucity of qualitative research examining key stakeholders' experience and management of recurrent sore throat. This study provides a unique opportunity to triangulate the perspectives of patients, GPs and ENT staff during a feasibility study for the NATional Trial of Tonsillectomy IN Adults (NATTINA) [17]. The specific objectives of the NATTINA feasibility study (Reference the linked NATTINA part 2 paper submitted separately) were to establish: standard NHS ENT staff willingness to randomise patients to the treatment arms; feasibility of patient identification and eligibility criteria; GPs' willingness to refer patients to standard NHS NATTINA centres; patients' willingness to be randomised and; views on the proposed data collection methods. Due to the richness of the data collected for the feasibility study, the reporting of stakeholder perspectives of sore throat and management was considered to be a stand-alone finding. This paper (part one of two linked NATTINA papers) aims to compare the views of these stakeholder groups to determine the impact of recurrent sore throats in adults and views of treatment pathways.

Methods

Ethical considerations

Transcriptions were anonymised and treated with strictest confidence. All identifying information was removed by giving each participant a unique code consisting of status: i.e. patient (p), ENT staff or GP and gender: male/female (M/F) which was used to attribute comments during analysis. Favourable ethical opinion was given by proportionate review sub-committee of the NRES committee – Fulham, London 16 June 2014 (14/LO/1115).

Design

In-depth qualitative interviews with ENT staff, referred ENT adult patients and GPs over a 5 month period.

Sampling

Purposive, seeking maximum variety in terms of location among men and women. A convenience sample of staff likely to be involved in (the nine centre) NATTINA trial (otolaryngologists, research nurses, nurse practitioners, clinic managers; with varying clinical expertise and roles) and GPs from the surrounding areas. Sample size was determined by reaching data saturation whereby no new themes emerged in three consecutive interviews [18]. Based on previous work [19], it was estimated that this would occur at around 45+ interviews: 20 ENT staff, 15 patients and 10 GPs.

Screening, recruitment and consent

Patients: ENT staff provided patients, attending referral visits, that met the proposed NATTINA eligibility criteria, [17] a Participant Information Sheet (PIS); considered to be the most efficient form of recruitment. One of the authors (LM) contacted patients who expressed interest and arranged interviews at a time and location convenient for them. Written informed consent was obtained at the beginning of the interview.

Patients received a shopping voucher to thank them for their participation.

ENT staff: Identified by the clinical investigator (CI). Staff were contacted by LM and provided with a PIS before being invited to participate in either a face-to-face or telephone interview. Verbal consent was taken at the time of the interview and signed consent returned post-interview (or at the beginning of the interview if taking place face-to-face).

GPs: Identified by the CI and consultants at the participating sites. GPs were contacted by LM and provided with a PIS before being invited to participate in a telephone interview. Verbal consent was taken at the time of the interview and signed consent returned post-interview.

Interviews

Patient interviews took place either at the recruited hospital site, the patient's home or place of work. One research nurse was interviewed at the hospital, all other ENT staff and GPs were interviewed by telephone. Semi-structured interviews were based on flexible topic guides derived from the literature, issues raised by our Patient and Public Involvement group and in conjunction with the study Otolaryngologist and GP. Themes explored included: symptoms, effects and management of recurrent sore throat, and experience of and willingness to participate in research.

Data management and analysis

Interviews were digitally audio recorded and transcribed verbatim. Framework analysis [20] was adopted as a recommended approach for qualitative health research with objectives linked to quantitative investigation [20]. NVivo software was used to aid coding [21]. Data were repeatedly read and coded independently by LM within a framework of a priori issues, those identified by participants or which emerged from the data. To minimise researcher bias, emergent themes were discussed with the qualitative lead and the study team. Using a framework method of verbatim quotes allowed for transparency of coding.

Results

Participants

22 ENT professionals (9 ENT consultants, 1 specialist registrar, 6 research nurses, 4 nurse practitioners and 2 trial managers), 15 patients with recurrent sore throats who had been referred to ENT and 11 GPs.

Effects of recurrent sore throat

Patients provided a comprehensive description of their recurrent sore throat symptoms:

A razor blade in my throat, that's the only way I can describe it. It was awful, I couldn't swallow, I couldn't eat, it hurt to talk (P087F)

Most patients spoke about symptoms associated with pain and difficulty swallowing. Several patients spoke of other symptoms such as fever, sore ears, halitosis and feeling drained.

When asked what type of symptoms patients reported to them, GPs described fewer symptoms, they were more likely to talk about symptoms directly associated with tonsils or secondary symptoms:

They may complain of temperature, of a headache, tiredness, referred pain to the ear. Those will be the main things (GP013M)

GPs also discussed individual patients' thresholds for discomfort and the subjective nature of pain. They rated the severity of the patient's symptoms by the difficulty the patient had with swallowing.

ENT staff tended not to highlight individual reported symptoms but described how they wanted confirmation from patients of how their symptoms affected them on a daily basis. Many consultants spoke of the use of the SIGN guidelines and the types of patients referred:

Most are seeing their GPs if they've got an acute sore throat. As I said they're only coming to see us if they are severely unwell
(ENT074M)

Therefore, although ENT staff spoke about how they wanted to 'build up a picture' of the patients' symptoms, they appeared confident with the GP's diagnosis and referral procedures.

Many patients reported their symptoms had an immense emotional impact; they spoke about feeling low in mood. Some reported feeling angry as having suffered from recurrent infections they were aware of the impact their illness would have on college or work. The majority of GPs did not feel that patients reported emotional effects of their symptoms:

In general most of my patients would present with more physical based symptoms (GP012F)

However one GP conceded that there was a 'psychological aspect' to suffering recurrent sore throats in that patients were anxious about absences from education or work. Similarly, although ENT staff did not discuss patients' emotional symptoms as such, they too acknowledged the patients' absence stress.

Impact of recurrent sore throat

Most patients reported being off education or work during sore throat episodes; this was described as frustrating and inconvenient. However, some patients reported serious consequences of their absences:

I don't get paid for being sick, so if when it happens, so then I'm struggling with money, I'm struggling with bills, to look after the children (P075F)

Another patient described how absences had triggered a formal work enquiry to investigate the frequency. Other patients explained that they tried to 'struggle on' by attending work but described not 'feeling 100 per cent'. GPs spoke about patients having to miss school or work as a motivating factor for their consultation:

The impact on either work or school and time spent not in school or work...I guess that's the motivating thing behind them coming into to see us as a GP (GP032F)

Likewise, ENT staff spoke of patients' concern of absences from school and work and threats of being dismissed as a motivation for removal of tonsils.

Only patients discussed the impact of their recurrent sore throats on social and/or family life. Younger patients reported missing out on seeing friends and being unable to go out at the weekend. Many spoke of family trips having to be cancelled during episodes of sore throat:

I've had to cancel a few trips to London because I've been so ill. All my family...it's quite important...so yes it's a lot of pressure (P041F)

Management of recurrent sore throats

Patients described self-management of symptoms; patients used over-the-counter medication and those suffering from tonsil stones would try to remove them:

Gargles, throat gargles with salt or with the Chlorhexidine mouthwash stuff. I've been using cotton buds to extract the stones
(P050F)

A small minority explained they would contact their GP as soon as their symptoms started:

If I do feel tonsillitis coming up I try to get to a GP as soon as possible, because the sooner you start the antibiotics the sooner it can stop it before it gets too bad (P044F)

However, many felt visiting their GP was pointless, they felt taking antibiotics was not effective for their symptoms or they reported being aware of antibiotic resistance. The majority who felt unable to cope with recurrent symptoms requested further help from their GP for other treatment options or by directly requesting a tonsillectomy. Some patients were aware of criteria they had to fulfil before being referred to secondary care, however, not all patients felt this was acceptable:

Yes she tries to force me [GP] "Oh it needs to be eight times" I said "No, no, no. No chance, I'm not going to have it eight times because this is my body. I'm up to five" (P040M)

A common theme among GPs was that adults presenting with recurrent sore throats was uncommon:

We don't see many patients as adults with recurrent tonsillitis. I don't know if that is simply because we don't see them because the way our system works because we have a minor injuries triage nurse. If

someone says, "I have a sore throat" and they are an adult, they probably don't come to us (GP012F)

Another GP reported how patients were more likely to self-medicate than previously. Types of management techniques used by GPs included: watchful waiting, advice about over-the-counter remedies and occasionally swabs were taken to determine bacterial infections. Many GPs reported using Centor clinical prediction score guidelines for the prescribing of antibiotics and sometimes a delayed antibiotic strategy was used. Although GPs stated that some patients who had previously been prescribed antibiotics had an expectation of getting them again for subsequent sore throats, most patients were reported as not expecting them:

If they know the antibiotics are going to maybe make a small difference or none at all, then quite a lot of them aren't that interested, I think, anymore. Some will be, but quite a lot are, I think here for an opinion rather than definite treatment (GP030M)

The overarching theme from GPs was that tonsillectomy was no longer a routine procedure:

I think a lot of people don't want a tonsillectomy anymore and I think it's been a long term, probably 10, 20 years of trying to unwind the idea that tonsillectomy is a good thing. And I think it is slowly coming through (GP030M)

Most GPs spoke of the revised guidelines and stricter thresholds for referring patients to ENT, others spoke of pressure to minimise referrals:

We do get feedback, and there's a practice board that reviews our referral rate. Certainly ear, nose and throat is one of the areas they look at... it would be pointed out if our referral rates were higher than others (GP026F)

If patients did not meet the criteria, they would not be referred at all:

We try really hard not to send our patients because for the vast majority of patients they are unlikely to have their tonsils removed as adults (GP012F)

However, one GP reported that some patients were unhappy with the criteria and requested quicker referrals. The majority of GPs reported that patients were most likely to initiate a referral conversation. If GPs did refer, they explained that they tried not to give patients the expectation of surgery but were simply referring for a specialist review.

ENT staff reported that tonsillitis was still considered to be “a common problem” among adults, however, referrals from primary care had become more complex:

A lot of patients are now expressing that they're seeing boundaries to accessing tonsillectomies as GPs are reluctant to refer the patient for the procedure (ENT074M)

As a result severe episodes of tonsillitis requiring hospitalisation were reported to be on the increase:

Generally, as ENT Surgeons, we primarily see these patients either when they're admitted acutely, usually by their GP or A&E, with a

severe exacerbation, when they're not eating and drinking

(ENT074M)

When assessing referred patients ENT staff would calculate their eligibility for surgery against the SIGN criteria. Others would use GP visit frequency and antibiotic use as a measure of severity. If patients failed the SIGN criteria they would be reviewed in 6 months to see if symptoms improved.

However, the majority of ENT staff were confident with the GPs' assessment of the referred patients and assumed they had followed the SIGN criteria.

Discussion

This qualitative study enabled triangulation of multiple views of recurrent sore throat, tonsillitis and their management to be compared, thus providing a unique insight from those who suffer from and deal with this debilitating condition.

Synopsis of key findings

The opinions expressed by patients suggest that recurrent sore throats in adults can have a significant effect on a patient's lifestyle resulting not only in physical symptoms but also a detrimental impact on work, family and social life. Younger patients in particular spoke about being unable to socialise. These findings are comparable with other qualitative work with children and their families [19, 22].

Patients described their symptoms in great detail while GPs were less descriptive and emotionally charged. This may be because patients do not report the emotional effects to their GP or that the GPs' focus is on SIGN guidance metrics [2]. Patients may only report work related effects of their symptoms because they feel this is more likely to lead to a referral to secondary care.

Patients also have to negotiate the potential barriers facing them in accessing treatment. However, the severity of their condition drove them to seek further advice for treatment. Most GPs believed that adult tonsillectomies were not a routine procedure and felt referrals were inappropriate. Several patients requested a referral to ENT with the hope of surgical intervention; many saw this as the final route.

It was evident that GPs follow the SIGN criteria [2] and many commented on changing thresholds which meant patients were having to report more sore throat episodes before being eligible for referral. However, most GPs felt that, perhaps due to the perceived lack of surgical intervention, this was appropriate. Some patients were aware that they had to fulfil criteria for referral but were unhappy with the process. ENT staff reported patients were finding access to secondary care more difficult with the higher thresholds. Furthermore, GPs reported not seeing many patients who suffered from recurrent sore throats, one explanation being that more patients were self-medicating. However, if patients are not reporting each tonsillitis episode, it will not be included in the eligibility criteria. ENT staff appear to accept GPs' use of the SIGN guidelines as being effective. As demonstrated in this study, long referral waiting times has a detrimental effect on patients' work and quality of life. A delayed diagnosis may result in more patients presenting with severe symptoms requiring hospitalisation [23].

Moreover, there presents a mismatch between GP perceptions; ENT reported seriousness of adult recurrent sore throats; increasing numbers of emergency admissions; and the numbers of adult tonsillectomies performed annually [9]. If indeed there is an estimated annual expenditure of £60 million in England for GP consultations and medical therapy [10] for sore throats, who is seeing these

patients? This paper highlights the importance of aligning the reported stakeholders' perceptions with reality.

Comparisons with other studies

Studies show that in terms of patient QOL tonsillectomy is an effective treatment. [11-13] [14, 15] [16]. In one study, 95% of patients found the operation effective in curing their sore throats and were appreciative of surgery [24]. Improved symptoms lead to a reduction in clinical visits, antibiotic prescriptions and work/education absences [14]. Despite GPs' belief that patients do not want or should not have surgical intervention, our results suggest otherwise. Patients do want to be given a choice and are willing to undertake the risk of surgery to potentially improve their symptoms and QOL. These findings are comparable with other qualitative work, [19] which reported that families wanted more choice and flexibility over the management of their child's recurrent sore throats.

Strengths and weaknesses

This study presents a depth of qualitative data from multiple stakeholders. The diverse views and opinions provided rich balanced data. Recruiting a convenience sample of GPs may limit the representativeness of the sample, furthermore, the generalisability of the study is limited to the UK health system.

Conclusions and recommendations

The literature reports a disparity between the number of adults with recurrent sore throats being seen by GPs and the recorded annual NHS spending on GP consultations and hospital admissions. GPs are aware that recurrent sore throats can impact patients' education and work but perhaps not the overall detriment on

social and family life. GPs are under pressure to reduce referrals and to curtail antibiotic prescribing [25] however, policy makers need to be aware of the severe consequences of recurrent sore throats in adults. Having access to effective treatment is paramount for patients. The role of tonsillectomy in adults needs to be re-assessed to determine whether it should continue to be ranked as a Procedure of Limited Clinical Effectiveness (PoLCE).

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